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The importance of HIV specialist services for African women living with HIV in Nottingham: results of a qualitative study

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Introduction

This article reports the results of a qualitative study of the experiences of African women living with HIV in Nottingham, UK.

Globally, sub-Saharan Africa is the region most severely affected by the HIV pandemic [1]. This pattern is also reflected in the UK where African migrants make up 27% of those diagnosed with HIV despite the fact that they constitute less than 1% of the population [2–4]. Healthcare staff play a central role in meeting the prevention and care needs of people living with HIV/AIDS [5]. In contexts of increasing migration, health workers are called upon to recognise the diverse cultural, social, economic and political histories of their patients, and to understand how these interface with their current living situation, including their HIV-related health and treatment needs [6].

Relatively little research has been conducted to investigate the health experiences of migrant populations living with HIV in the UK, or on their patterns of access to, and utilisation of, HIV treatment and care [7]. Findings from the available, but limited, studies indicate that African migrants tend to present later than other population groups for HIV testing and treatment [8]. This is attributed to a number of obstacles to seeking or accessing care, including individual/community characteristics (such as AIDS-associated stigma, lack of perceived risk and denial), and factors associated with service and welfare provision in the host country – such as perceived discrimination, language and cultural differences, financial constraints and uncertain legal/immigration status [8–10].

Migrant African communities in the UK have traditionally congregated in London, where a large range of HIV specialist medical and community-based services are available, and where material and social resources can be accessed through existing social networks. It is estimated that 81% of HIV-infected Africans live in London [4]. This situation is slowly changing however, attributed in part to the Government's policy of 'dispersal' whereby, since 1999, asylum seekers have been 'dispersed' to locations across the country. Questions have been raised as to whether HIV services outside the capital are able to provide specialist care that is appropriate and accessible for African migrant groups. Very little research has been done, however, to explore the experiences of HIV-positive Africans living outside London [10–12].

African women and HIV

In the UK, women accounted for 65% of new HIV diagnoses made in 2003, of which more than 70% were African [2].[1] **1. A breakdown of more recent figures that combines gender and nationality is not available in the latest Health Protection Agency (2008) report.** Most of the research on HIV and migrant African communities in the UK however has focused upon men, or has utilised mixed-gender samples [10,13]. Only one study has explicitly focused on African women and it drew its sample exclusively from London [14,15]. This study showed that, although not a homogeneous group, African women's experiences of living with HIV were shaped heavily by their socio-economic circumstances, by the responsibilities of motherhood and by their immigration status. In situations where women were living in relative poverty and where their immigration status was insecure, health concerns were overshadowed by more immediate survival concerns. In addition, given the limited treatment availability in African countries, for many women, staying in the UK represented their only opportunity of access to HIV treatment. Thus, some women appeared trapped in a catch-22 – even when life in the UK was difficult, going back home was no longer an option. This study [15] also highlighted the fact that HIV/AIDS remains a heavily stigmatised disease, and that fear of HIV-related stigma affected women's ability to access social support, both from family and friends or from the voluntary sector.

In order to ensure equity of access to healthcare based on gender and on locality, there is a need for more research to examine the experience of African women living with HIV in the UK and, in particular, to consider the nature of this experience for those living in areas that are less well served with specialist HIV statutory and voluntary services. Our study aimed to investigate these issues in the central English city of Nottingham. The study aimed to explore: (i) African women's experiences of coping with HIV; and (ii) their views on the city's HIV services. This paper focuses primarily on the latter issue – women's views of service provision. A fuller account of the research can be found in Ndirangu and Evans [16].

Research setting

Nottingham is the economic and cultural capital of the East Midlands area of the UK and has a population of approximately 625,000 people of whom 81.1% are classified as white-British and 15.1% are from other ethnic groups. There has been a 494% increase in new HIV diagnoses in the East Midlands region in the last decade [3]. According to the latest available cumulative figures, 412 people in Nottingham City PCT have been diagnosed with HIV, of whom 49% are African. Forty-five percent of the people living with HIV/AIDS are female, of whom 71% (n = 89) are African [3,17]. HIV services in Nottingham are delivered through two different hospital clinics based in an Infectious Diseases Unit and a Genitourinary Medicine Unit. These services are supported by a multidisciplinary, community-based 'Positive Care team' (comprising a specialist nurse, a social worker, a dietitian, a community care officer and a befriending service coordinator).[2] **2. This team now also includes a Terrence Higgins Trust Centre, but this was not available at the time of the research.** The Positive Care team runs a weekly 'drop-in centre' where people living with HIV/AIDS can come to socialise and access professional help on an informal basis. The voluntary sector in Nottingham is small, comprising two refugee support groups and one HIV-related support group that is run by non-Africans. There are no African-focused HIV-related community organisations.

Methods

The research adopted a qualitative approach, using semi-structured interviews to ask migrant African women in Nottingham about their experiences of coming to the UK, the impact of HIV/AIDS, sources of support, coping with everyday life and views on health services [18]. Data was collected in 2005. The sample comprised eight African women from three different countries; Congo (n=1), Malawi (n=2) and Zimbabwe (n=5). They represented approximately 10% of Nottingham's female African HIV-positive population. English-speaking women aged 18–50 were recruited opportunistically via the hospital or drop-in centre with the help of the Positive Care team. Some interviews took place in women's homes, and some were held in the hospital. Ethical approval was obtained from the local National Health Service Research and Ethics Committee. Great care was taken to ensure that participants understood the nature of the study. They were assured that their participation was entirely voluntary, that it would not affect their care in any way, and that their views would remain strictly anonymous. Arrangements were made for psychological care in case anyone became distressed; however, recourse to this provision was not required.

The interviews were conducted by the first author (a Kenyan nurse who was at that time studying for an MSc). The interviews were audio-taped and transcribed. Data was analysed thematically using framework analysis [18–20]. Three themes are considered here: (i) living with HIV as a migrant; (ii) HIV stigma and social support; and (iii) the role of health services.

The sample

Two participants were students, four were asylum seekers and two had 'indefinite leave to remain' in the UK. All were aged between 30 and 50 years. Five participants had studied to secondary school level. The students were in part-time employment and one participant was in full-time work. The asylum seekers were barred from working and had to rely on state benefits, which (as will be described below) were judged insufficient. Women gave a variety of reasons for migration, including fleeing from war (1), political insecurities (2), pursuit of work (1), visiting relatives (2) and education (2). All participants had been in the UK for a relatively short period of time (between 1 and 5 years) and were still trying to adjust to the new environment. The majority of the participants had initially come to the UK alone, although a few of the women were later joined by some or all of their children or a husband. None the less, they found themselves without the close social and family networks that are characteristic of the African setting.

The majority of women (7) had children, four of whom had children living in the UK. The children of the other three women were still in Africa living with relatives, but were depending upon the participants for financial help. The majority of the women were the main providers and care-givers for their children, both in the UK and back home. Half of the women had been divorced prior to coming to the UK, two participants were single and had never been married, while one was widowed. Thus, most of the women were single parents with no informal psychosocial support from a partner.

The majority of the group had been HIV-positive for a period of 1–4 years.

Results

Living with HIV as a migrant

The impact of migration on the participants' health was varied and depended upon their migration status, reasons for coming to the UK and the kind of life they had back home. For the asylum seekers, lack of legal status meant that they had to live with the uncertainty of being sent back home and that they might lose access to life-saving treatment:

> *My head is not well, I am not thinking properly because of problems of immigration. (P5)*

> *If I had a choice, I wouldn't be here – I can't go back home because where will I get my*

medication from if I go back home? What will happen to my daughter? (P6)

The view of the life in the UK depended on their previous life back home and on their current circumstances in the UK. For participants who had left difficult circumstances back home, they were grateful for the basic facilities and security that they now had:

Oh! The good day is that when I found accommodation here. I live well, everything was there, I wash my body, you are free, I had food, I sleep well with blankets, the clothes was there, everything was there. The support was there, so everything is good for me. (P2)

On the other hand, asylum seekers were struggling financially as they tried to use their meagre state welfare benefits to support themselves and their kin both in the UK and in Africa. In their view, work would help them improve their economic situation while at the same time give them a sense of normalcy and general well-being:

I was refused you know because asylum seekers are not allowed to work. You have to sit just like I am sitting, may be that is why… sometimes I think that is why I got this venous thrombosis. You know back home we work, we were working very hard. (P3)

Some of the participants had past traumatic experiences in their countries of origin that clearly affected their emotional well-being:

When they killed my mother, my father and my two brothers went to [name of home town] and I have not received any news about them. I worry if they are alive or they have already died. This is what makes me have a headache. (P5)

HIV stigma and social support

Many women in the study described how HIV-related stigma hindered them from accessing social and psychological support. A number of women kept their diagnosis a secret, particularly from others in their own countries/communities. In their view, they felt that people associated HIV with immorality and would thus view them as being immoral and undeserving of any help:

They think that maybe you used to go around with many men – you see, they will think that and won't think anything else – they will think you are a prostitute. (P5)

No, I didn't tell anyone. Because who can I tell? I will tell my friend and then she will tell another… then all the people from your country will know that you are sick. Then they will start to talk and you will feel bad. That is why I do not tell anyone. (P4)

Some of the asylum seekers in particular seemed lonely and socially isolated, and their situation was exacerbated by being housed in poor accommodation in 'rough' parts of the city. In these difficult circumstances, some women noted that their childcare responsibilities and love for their children were the key factors that kept them going:

Everything is for the children, the children you know. I haven't got time for myself really, when they told me. Since then, I do not feel well – sometimes I think to myself to drink all the medicine and die, but when I look at my children there, I know it's worth it. (P5)

As noted in other studies (e.g. [21]), all the participants attended church and found great comfort in their faith.

Role of the HIV services

Significantly, health and social care services were the most common source of support for the participants – as reported in other studies from the UK [15]. Many participants depended on the Positive Care team for support with issues such as getting a solicitor for their immigration problems, housing and obtaining benefits. Healthcare providers were said to be the most preferred source of support because they already knew about HIV and could offer tailored support:

Ooh! The first days I am crying when I get illness. Oh! My Lord……my children… but [the social worker] said to me 'No, no you will get better'. (P2)

All the participants seemed to be extremely satisfied with the care they received and two participants contrasted their specialist care with previous more negative experiences of GP care.

I used to go to the GP but then her actions were not pleasing enough. So when I explained to the doctor at [name of hospital] they said if am unwell I should just rush to the hospital for treatment – At the GPs, they will say come tomorrow or maybe this medication… you will not find this medication in the pharmacy and so on. Such words are not encouraging to a patient. (P7)

Women's expressed satisfaction with their healthcare appeared to be reinforced by the obvious contrast in health services between their country of origin and the UK. Some participants reported coming from situations where there is a lack of resources and where they have experienced stigma and discrimination, especially from healthcare workers. For example, one participant described the care her boyfriend had received in Africa:

In Africa there is no medication and they are not too good in hospitals. They won't treat you very well. Here doctors are very careful, yes they I don't know what to say, each time you go for check up. But back home check up is on

your first day, that's it until you die. (P1)

Participants cited the drop-in clinic as being a particularly useful source of support. Although the drop-in is not specific for African women living with HIV/AIDS, it offered the participants a chance to meet other HIV-positive people and to share and learn more from them. Participants using the drop-in clinic seemed to cope better with being HIV-positive than the participants who did not use this service.

Here at the drop in – most helpful – because they [drop-in] teach me how to practice safe sex and how to look after my body. (P1)

The drop-in, it brings people together to talk about what is worrying them. There are specialists to provide help especially for those recently diagnosed it is a source of motivation from success stories. (P8)

But as it is now…. You know when I went there [drop-in] the people I was seeing there are the people I was seeing when I go to [name of hospital]. So my mind says 'oh this people maybe they are like me'. (P3)

However, probably due to fears about confidentiality and stigma, the participants were universally adamant that they did not want a support group specifically for African women. This seems to contradict findings from other studies which indicate that African community organisations can play a major role in supporting African people living with HIV in the UK [11,22].

Discussion

This brief research report reiterates the challenges that HIV-positive African women in the UK may face in disclosing their status and accessing support due to stigma, uncertain legal status and difficult social/economic circumstances [2,5,15]. The need for secrecy can lead to physical and emotional isolation as women struggle to keep their HIV status a secret. The loss of social networks and/or not wanting to establish new ones means that African women may rely heavily on health/social care workers for support. Significantly, in this small study, the health service was represented as the only safe social space in which women could access non-judgemental care and support. Women appeared to be extremely satisfied with the care they received and did not report any significant barriers to accessing care. This is undoubtedly partly due to the multidisciplinary nature of service provision in which specialised medical, social welfare and nursing support was available in one location. The dedication of the those in the Positive Care team and drop-in facility was also recognised.

A key implication from this study is that in geographical areas such as Nottingham where the voluntary sector contribution to HIV care is limited, it is important that statutory HIV services recognise the potentially critical role they play in supporting this patient group, and ensure that adequate staff time and resources are made available to continue this effort.

Conclusion

In conclusion, HIV services in the UK appear to play a central role in meeting the needs of African women living with HIV/AIDS [11,14]. Coming from a context where HIV/AIDS is still heavily stigmatised, African migrant women appear to highly value care that is non-judgmental, personalised and kind. However, as with all nursing care, it is important to recognise that African immigrant women are not a homogeneous group but rather have unique and varied needs, different experiences and expectations from healthcare services. Assessment of each individual remains crucial [9].

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References

1. UNAIDS. *Report on the Global AIDS Epidemic*. UNAIDS, Geneva, 2008.
2. Department of Health. *HIV and AIDS in African Communities: A Framework for Better Prevention and Care*. Department of Health, London, 2005.
3. Health Protection Agency. HIV in the UK. 2008 **{further details/web address?}**
4. Sinka K, Mortimer J, Evans B, Morgan D. Impact of the HIV Epidemic in sub-Saharan Africa on the pattern of HIV in the UK. *AIDS*, 2003, **17,** 1683–1690.
5. Burns F, Imrie J, Nazroo J *et al*. Why the(y) wait? Key informant understandings of factors contributing to late presentation and poor utilisation of HIV health and social care services by African migrants in Britain. *AIDS Care*, 2007, **19**, 102–108.
6. Quickfall J. Developing a model of culturally competent primary care nursing for asylum applicants and refugees in Scotland: a review of the literature. *Diversity Health Soc Care*, 2004, **1**, 53–64.
7. Amo J, Broring G, Fenton K. HIV health experiences among migrant Africans in Europe: how are we doing? *AIDS*, 2003, **17**, 2261–2263.
8. Burns F, Fenton K. Access to HIV care among migrant Africans in Britain: what are the issues? *Psychol Health Med*, 2006, **11**, 117–125.
9. Watson S. Asylum seekers and refugees: issues regarding assessment. *HIV Nurs*, 2008, **8**(4), 8–11.
10. Weatherburn P, Ssanyu-Sseruma W, Hickson F *et al*. *Project Nasah: An Investigation into the HIV Treatment Information and needs of African People Living with HIV Resident in England*. Sigma Research, London, 2003. Available at www.sigmaresearch.org.uk/go.php/projects/african/project19 (last accessed 24th February 2009).
11. Allan C, Clarke J. Are HIV/AIDS services in Leeds UK able to meet the needs of asylum seekers? *Public Health*, 2005, **119**, 305–311.
12. Gazzard B, Anderson J, Ainsworth J, Wood C. *Treat with Respect: HIV, Public Health and Immigration*. Kings Fund, London, 2005. Available at www.library.nhs.uk/healthmanagement/ViewResource.aspx?resID=264516 (last

accessed 24th February 2009).

13. Erwin J, Peters B. Treatment issues for HIV positive Africans in London. *Soc Sci Med*, 1999, **49**, 1519–1528.
14. Anderson J, Doyal L. Women from Africa living with HIV in London: a descriptive study. *AIDS Care*, 2004, **16**, 95–105.
15. Doyal L, Anderson J. 'My fear is to fall in love again…' How HIV-positive African women survive in London. *Soc Sci Med*, 2005, **60**, 1729–1738.
16. Ndirangu E, Evans C. Experiences of African immigrant women living with HIV in the UK: implications for health professionals. *J Immigrant Minority Health*, 2009, in Press. DOI 10.1007/s10903-008-9116-8.
17. Dodds C, Weatherburn P. *Supporting People with HIV: Research into the Housing and Related Support Needs of People with HIV in Nottingham City*. Sigma Research, London, 2006. Available at www.sigmaresearch.org.uk/downloads/report06a.pdf (last accessed 24th February 2009).
18. Green J, Thorogood N. *Qualitative Methods for Health Research*. Sage, London, 2004.
19. Bryman A, Burgess R. *Analysing Qualitative Data*. Routledge, London, 1994.
20. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: *Analysing Qualitative Data* (Bryman A, Burgess R, eds). Routledge, London, 1994; pp 173–195.
21. Chinouya M, O'Keefe E. God will look after us: Africans, HIV and religion in Milton Keynes. *Diversity Health Social Care*, 2005, **2**, 177–186.
22. Chinouya M. *HIV Prevention and African Communities Living in England: A Framework for Action*. National AIDS Trust, 2001. **{Further details such as Web address??}**

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